Statistics on Stroke

A Pilot Study of the Clinical Evidence Justifying the Reporting of Stroke on Death Certificates in Alameda County, California

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THE MAGNITUDE OF the stroke problem is to some extent reflected in the fact that stroke ranks third as a cause of death in the United States, and that in 1962 the total economic cost of strokes to the nation as estimated in The President's Report stood at \$1.1 billion.7 Furthermore, while in 1963 some 80 percent of the stroke deaths occurred in people aged 65 and over, stroke also claimed 38,337 persons under 65.10 A reliable estimation of the extent of the stroke problem is necessary to provide a basis for judging changes in stroke mortality and thereby more effectively evaluate preventive and therapeutic techniques.

Mortality data seem to be a ready source of such information, but problems such as the accuracy of diagnosis, the completeness of reporting, and whether stroke is coded as the underlying cause of death when several pathological conditions are contributing to the death of the patient make it difficult to obtain reliable estimates of mortality from stroke. A number of reports concerned with the epidemiology of stroke have made use of the information contained on death certificates.1-4,9,12-14 The value of such studies is, however, a direct function of the reliability of the information on the death certificate. The most extensive analysis which has been made of death

This paper reports on a pilot study, in which a very small sample of death certificates is analyzed according to neurological criteria, which together with the diagnosis appearing on the clinical record form the basis of estimating false positive and false negative rates of diagnosis listed on the death certificate. The study was designed to answer the following questions:

- Problem of false positives: Has a diagnosis of stroke been entered on the death certificate without any apparent justification, as judged by the patient's previous history (obtained from hospital, nursing home or coroner's records)?
- Problem of false negatives: In cases where stroke is not mentioned on the death certificate, has a stroke occurred as judged by the clinical evidence or mention of stroke in the patient's previous history?

certificate information in the United States was carried out in Pennsylvania by Moriyama and coworkers in 1958.6 These investigators did not confine their interest to cerebrovascular accidents, although they did include this group of diseases among the several which they studied. They did not explicitly state their criteria for the evaluation of the quality and certainty of diagnosis, and although they did estimate the frequency with which persons who die of conditions other than stroke are falsely assumed to have died of stroke, they did not record the frequency with which actual stroke deaths are reported as having been due to other causes. In other words, they estimated the false positive rate, but not the false negative rate.

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• In the case of true positives, what proportion appears in the tabulation of vital statistics, which, of course, uses only one diagnosis from each certificate?

Material and Methods

Cases: The sample was drawn from copies of death certificates issued in Alameda County, California, in April, 1965. In all, there were 94 certificates in which stroke was listed as the immediate cause of death, as one of the underlying causes of death, or as a contributory cause of death. Of these, 87 concerned deaths which had occurred in medical institutions, and seven concerned deaths at home. Since the time for field work was very limited, it was necessary to restrict our attention to cases in which death occurred in a medical institution (hospital or nursing home) in which more than one such death had occurred. This meant that 28 certificates were omitted from the sample. Of the remaining 66 certificates, one more had to be excluded because no clinical record was available. These details are summarized in Table 1.

Controls: A control group was selected by matching each certificate in the stroke series with another in which the underlying cause of death had been coded under the hypertensive and cardio-vascular diseases, rubrics 420-459 of the *International Classification of Diseases*, 1955 Revision.¹¹ Throughout this report, the coded underlying cause of death refers to the one coded by Alameda County and is not necessarily the one appearing in the national statistics. The matching was done on the basis of age, sex, race and place of death (hospital or nursing home). Categories

TABLE 1. — The Sample of "Stroke Deaths" Used in Study of Evidence Warranting Reporting of Stroke on Death Certificates

Died at home	7	
Single deaths occurring in any given hospital.	1	
Single deaths occurring in any given nursing home	20	
Eligible nursing home death: record not available	_1	
Total number of cases not studied	29	29
Eligible nursing home deaths	15	
Eligible hospital deaths	50	
Total number of cases studied	65	65
Total number of cases		94
Total in matched control sample	65	
Total studied	130	

420-459 were chosen as the non-stroke group among which the majority of false negatives might occur, because after an examination of the death certificates in the stroke group (rubrics 330-334), it was found that cardiovascular and hypertensive diseases are the conditions most often associated with stroke on death certificates. This was not surprising since it is a long established medical fact that cerebral hemorrhage is a complication of hypertension,8 and it has recently been shown that cerebral thrombosis is most likely to occur in persons who already have hypertension or electrocardiographic abnormalities.5 This particular set of controls would therefore increase the chances of finding evidence for stroke in the medical records although stroke was not mentioned on the death certificate. In other words, our selected nonstroke group was biased toward a higher proportion of false negatives than the general non-stroke population that had died in Alameda County in April, 1965.

Record Abstraction

In consultation with Dr. William Drake of the University of California School of Medicine and Dr. John Cutler of the University of California School of Public Health, a series of criteria was drawn up which would serve as a basis for deciding whether a diagnosis of cerebrovascular accident appeared to be justified. Further details of these criteria are listed in the appendix.

Results

The following definitions were used to determine the presence or absence of stroke by reference to the clinical record: 1) determined by our own criteria and 2) named as such on the hospital or nursing home chart.

False positives were considered to be cases in which stroke was listed as such on the death certificate, but which did not meet our own criteria (definition 1, see Table 2) or in which stroke was not mentioned as a diagnosis on the medical record (definition 2, see Table 3). Tables 2 and 3 show how many false positives and false negatives were found in relation to whether the death occurred in a hospital or a nursing home. In reference to definition 1, there was one (2 percent) false positive in the hospital group of stroke-associated deaths surveyed, while in the nursing homes there were seven (46.7 percent) false positives. In reference to definition 2, there were four (8 per-

TABLE 2.—Comparison Between Death Certificates Listing Stroke and Detailed Review of Clinical Record

•		CASES (Stroke listed on death certificate)						CONTROLS (Stroke not listed on death certificate)				
Result of Clinical review	Hospital Death		Nursing Home Death		Total		Hospital Death		Nursing Home Death		Tot	tal
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Stroke by our criteria	46	92.0	7	46.7	53	81.5	11	22.0	3	20.0	14	21.5
Questionable stroke by our criteria		6.0	1	6.7	4	6.2	5	10.0	5	33.3	10	15.4
Not stroke by our criteria.	_1	2.0	7	46.7	_8	12.3	34	68.0	_7	46.7	41	63.1
TOTALS	50		15		65		50		15		65	

cent) false positives in the hospital group of strokeassociated deaths surveyed, while in the nursing homes there were six (40 percent) false positives.

False negatives were taken as death certificates on which stroke was not listed, yet the medical records contained information which met our criteria for stroke (definition 1), or actually listed stroke as a diagnosis (definition 2). There were 11 (22 percent) false negatives in the hospital group of non-stroke deaths surveyed, and there were three (20 percent) false negatives in the nursing home group by definition 1. In reference to definition 2, there were eight (16 percent) false negatives in the hospital group, and three (20 percent) false negatives in the nursing home group.

Tables 4 and 5 show the proportion of true positives that appears in vital statistics data listing stroke as the underlying cause of death. Combining definitions 1 and 2 to determine the presence of stroke, two definitions for true positives can be formulated. The weaker definition would include any death which either met our criteria for stroke or had stroke listed as such on the clinical record. There were 78 such deaths in our sample, and 35 (44.9 percent) of these had stroke coded as the underlying cause of death (see Table 4). The stronger definition of a true positive would include any death which met our criteria for stroke and had stroke listed as such on the clinical record.

There were 55 such deaths in our study, and 30 (54.5 percent) of these had stroke coded as the underlying cause of death (see Table 5).

Discussion

It should be pointed out that this report is but a pilot study intended to develop a method and it is hoped that publication of this additional effort will stimulate the interest of others in this field. The data were drawn from a single county during a single month, and any generalizations must be guarded.

There was a higher percentage of false positives in the nursing home deaths than in the deaths occurring in hospitals according to both definitions 1 and 2. This was to be expected, since the nursing home records often had little information to justify a diagnosis of stroke and often made no mention of stroke at all. These nursing home records, with their lack of detail, should have the opposite effect in the case of false negatives, which rely on the failure to list stroke on the death certificate and the presence of clinical evidence for a diagnosis of stroke or the actual mention of stroke on the clinical record. However, the percentage of false negatives according to either definition 1 or 2 was about the same for the hospital deaths and the nursing home deaths.

As would be expected, the percentage of cases

TABLE 3.—Comparison Between Death Certificate and Clinical Diagnosis CASES
(Stroke listed on death certificate) CONTROLS listed on death certificate) (Stroke not Hospital Nursing home Death Hospital Nursing bome Total Total % No. % No. No. No. % Stroke diagnosed clinically (stroke listed on the clinical record) 92.0 60.0 55 84.6 16.0 20.0 11 16.9 Stroke not diagnosed clinically (stroke not listed on the clinical record) 8.0 40.0 10 42 80.0 15.4 84.0 12 83.1 TOTALS 15 65 50 15 65

TABLE 4.—Comparison Between Clinical Strokes by the Weaker Definition and Deaths Coded* as Being Due to Stroke
—Controls and Cases Combined

	Stroke d underlyi of d	oded as ng cause eath	Stroke not underlying dea	cause of	Total	
	No.	%	No.	%	No.	%
Stroke diagnosis appearing on chart or meeting our criteria, or both	35	44.9	43	55.1	78	100
Stroke diagnosis not mentioned on chart and not meeting our criteria	4	7.7	48	92.3	52	100

Of 65 strokes listed on death certificates 39 (60%) were coded as the underlying cause of death.

*The coded cause of death refers to the one coded by Alameda County and is not necessarily the one appearing in the national vital statistics.

in which stroke was coded as the underlying cause of death was higher in association with the stronger definition of true positive than with the weaker definition. The stronger definition would probably include strokes with the most overt symptoms and would exclude more strokes with less clinical justification for the diagnosis. One would anticipate, then, that these more overt and easily diagnosed strokes would be a major factor in the death of the patient, and as such would be more often coded as the underlying cause of death than would the less overt strokes.

It is not possible to say whether the records which were not studied (those of stroke cases in which death occurred at home or cases that were the only stroke death occurring in a given medical institution in the month of April, 1965) were more accurate than the ones which were studied. However, since most of the larger institutions were included in the study, it seems likely that, if anything, the accuracy of death certificates listing stroke has been overestimated in this report.

The percentage of true positive strokes associated with death that eventually are recorded in vital statistics data would be increased if publications of mortality data gave tabulations which took into account secondary underlying and contributory causes of death. Not only would the publication of such tabulations improve estimates of rates, but it would also provide data which would permit

more accurate descriptive analysis of epidemiologic factors in cerebrovascular accidents.

APPENDIX

In all parts of this report, the term stroke is used to refer to all diseases listed under rubrics 330-334 of the International Classification of Diseases 1955 Revision, W.H.O. All other codes for diseases are from the same source.

With any of the criteria listed below, the evidence for stroke was accepted only if the clinical or anatomical lesion was not directly attributable to an infectious process involving the brain or meninges, to a tumor, to a demyelinating disease, or to physical trauma.

Criteria for Stroke:

- 1) If any of the following were present in the information on the clinical record, the deceased was considered to have had a stroke:
- a) Postmortem evidence to support a diagnosis of stroke
- b) Surgical evidence to support a diagnosis of stroke
- c) Non-traumatic lumbar puncture with bloody cerebrospinal fluid
 - d) Angiographic evidence for stroke
- e) Brain stem involvement (functional disturbances attributable to brain stem damage)
 - f) Coma
 - 2) If none of the above criteria were mentioned

TABLE 5.—Comparison Between Clinical Strokes by the Stronger Definition and Deaths Coded* as Being Due to Stroke
—Controls and Cases Combined

	Stroke o underlyi of d	coded as ng cause eath	Stroke no as unde cause of	erlying	Total		
	No.	%	No.	%	No.	%	
Stroke diagnosis appearing on chart and meeting our criteria	30	54.5	25	45.5	55	100	
Stroke diagnosis not mentioned on chart or not meeting our criteria, or both	9	12.0	66	88.0	75	100	

The coded cause of death refers to the one coded by Alameda County and is not necessarily the one appearing in the national vital statistics.

on the clinical record, but if any of the following chart information was listed, the decedent was considered to have had a questionable stroke:

- a) Nuchal rigidity
- b) Loss of motor function
- c) Deep tendon reflex changes
- d) Pathological reflex and/or clonus
- 3) If none of the criteria listed in 1) or 2) above appeared in the clinical record, then there was not sufficient evidence to say the decedent had a stroke.

REFERENCES

- 1. Acheson, R. M.: Mortality from cerebrovascular accidents and hypertension in the Republic of Ireland, Brit. J. Prev. Soc. Med., 14:139-147, July 1960.
- 2. Acheson, R. M.: Mortality from cerebrovascular disease in the United States, Public Health Monograph, 76:23-40, 1966.

 3. Borhani, N. O.: Changes and geographical distribution of mortality from cerebrovascular disease, Amer. J. Public Health, 55:673-681, May 1965.

- 4. Goldberg, I. D. and Kurland, L. T.: Mortality in 33 countries from diseases of the nervous system, World Neurology, 3:444-465, June 1962.
- 5. Kannel, W. B., Dawber, T. R., Cohen, M. E., and McNamara, P. M.: Vascular disease of the brain—epidemiologic aspects: the Framingham Study, Amer. J. Public Health, 55:1355-1365, Sept. 1965.
- 6. Moriyama, I. M., Baum, W. S., Haenzel, W. M., and Mattison, B. F.: Inquiry into diagnostic evidence supporting medical certifications of death, Amer. J. Public Health, 48:1376-1387, Oct. 1958.
- 7. President's Commission on Heart Disease, Cancer and Stroke: Report to the President: A national program to conquer heart disease, cancer and stroke, U.S. Government Printing Office, Washington, D.C., vol. 1, Dec. 1964, p. 13.
- 8. Ross Russel, R. W.: Observations on intracerebral aneurysms, Brain, 86:425-442, 1963.
- 9. Stallones, R. A.: The epidemiology of cerebrovascular disease, J. Chronic Dis., 18:859-872, Aug. 1965.

 10. Vital Statistics of the United States: 1963, U.S. Government Printing Office, Washington, D.C., vol. II, part A, 1965, pp. 1-114-115
- 11. World Health Organization: International classification of diseases: Manual of the international statistical classification of diseases, injuries, and causes of death, World Health Organization, Geneva, vol. 1, 1957.
- 12. Wylie, C. M.: Cerebrovascular accident deaths in the United States and England and Wales, J. Chronic Dis., 15:85-90, Jan. 1962.
- 13. Wylie, C. M.: Recent trends in mortality from cerebrovascular accidents in the United States, J. Chronic Dis., 14:213-220, Aug.
- 14. Yates, P. O.: A change in the pattern of cerebrovascular disease, Lancet, 1:65-69, 11 Jan. 1964.